



HEALTH ADVOCACY

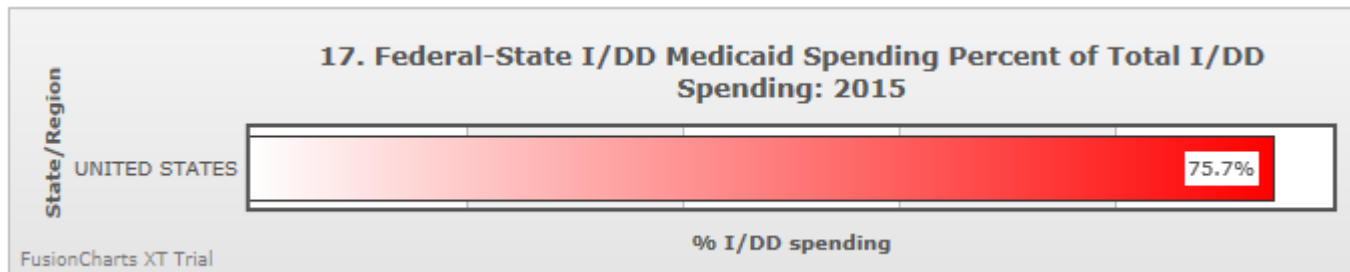
It's everyone's responsibility!

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The Resource Exchange
Developmental Disabilities Health Center

Context



- 4.71 million humans in the US have an IDD
- \$65.2 billion in total public spending in LTSS for IDD
 - \$39.2 billion Medicaid waiver and related
 - \$10.4 billion in ICF/IID
 - \$15.6 billion non-Medicaid

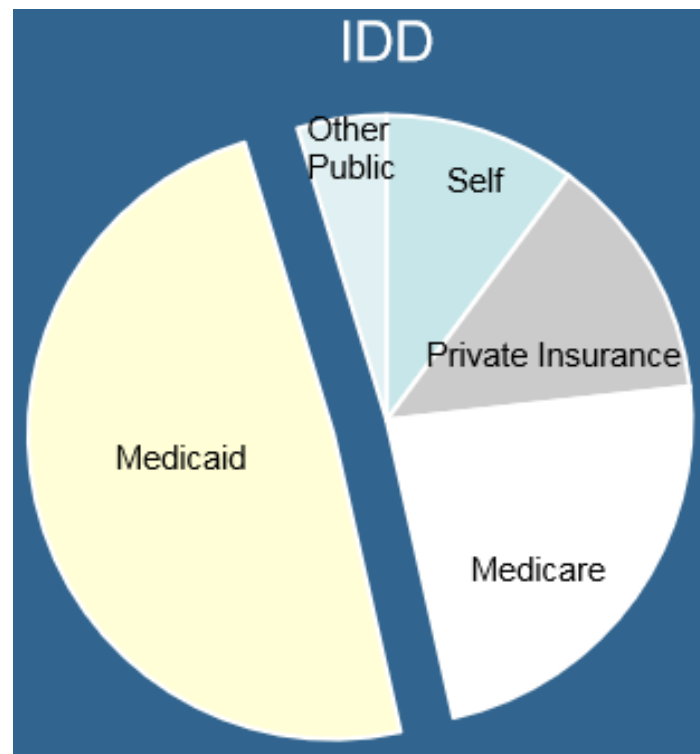


Context



Cost of healthcare for Americans with IDD

- \$4.24 billion
 - 39% medication (\$1.7 billion)

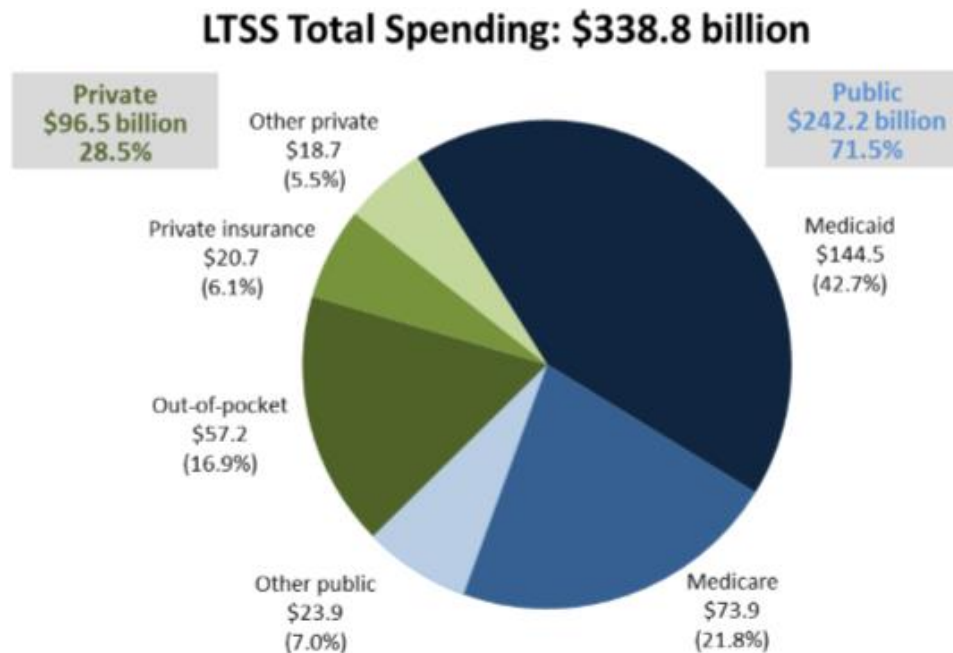


Context



National LTSS Spending

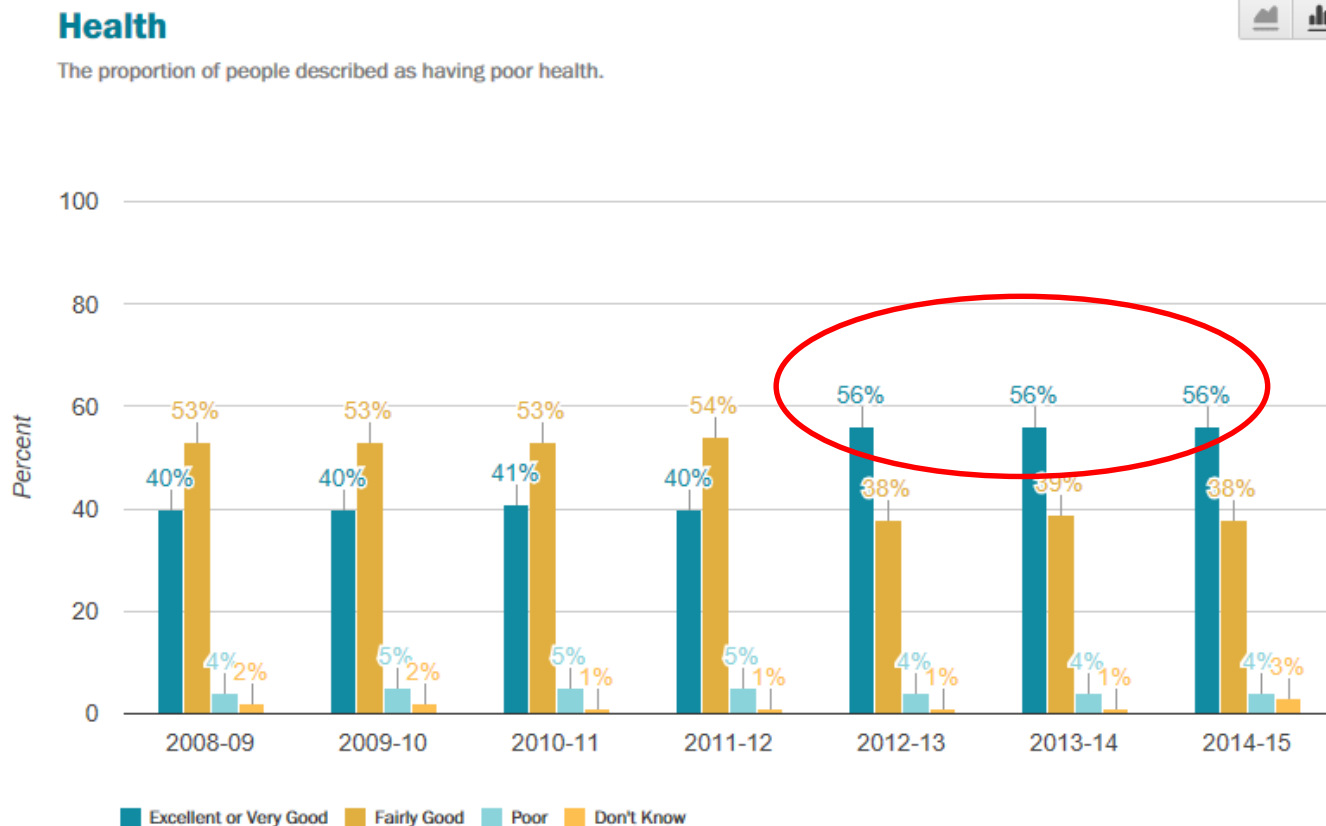
- \$65.2 billion IDD services (19-20%)
- 12 million ppl total 2010
- 27 million ppl total by 2050



Context



- 741,285 HCBS Waiver participants
- Nearly 900,000 living with aging caregivers

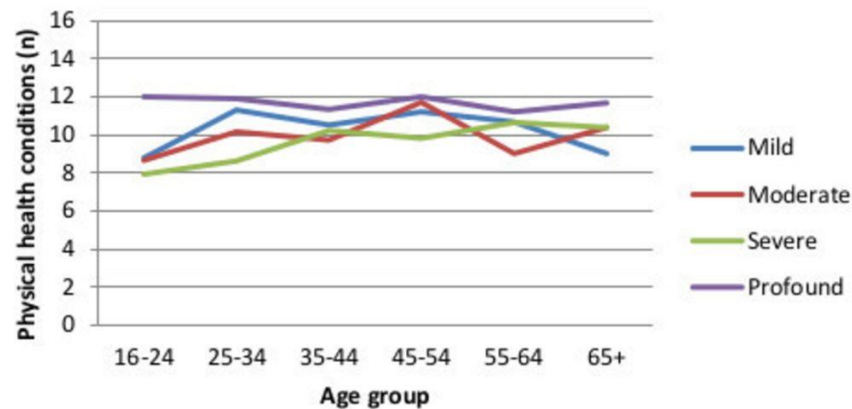


Health Status



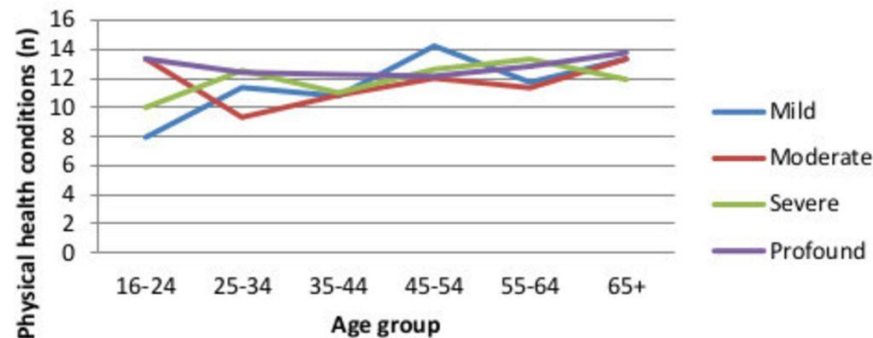
Men

Mean number of physical health conditions by age group and level of intellectual disabilities



Women

Mean number of physical health conditions by age group and level of intellectual disabilities

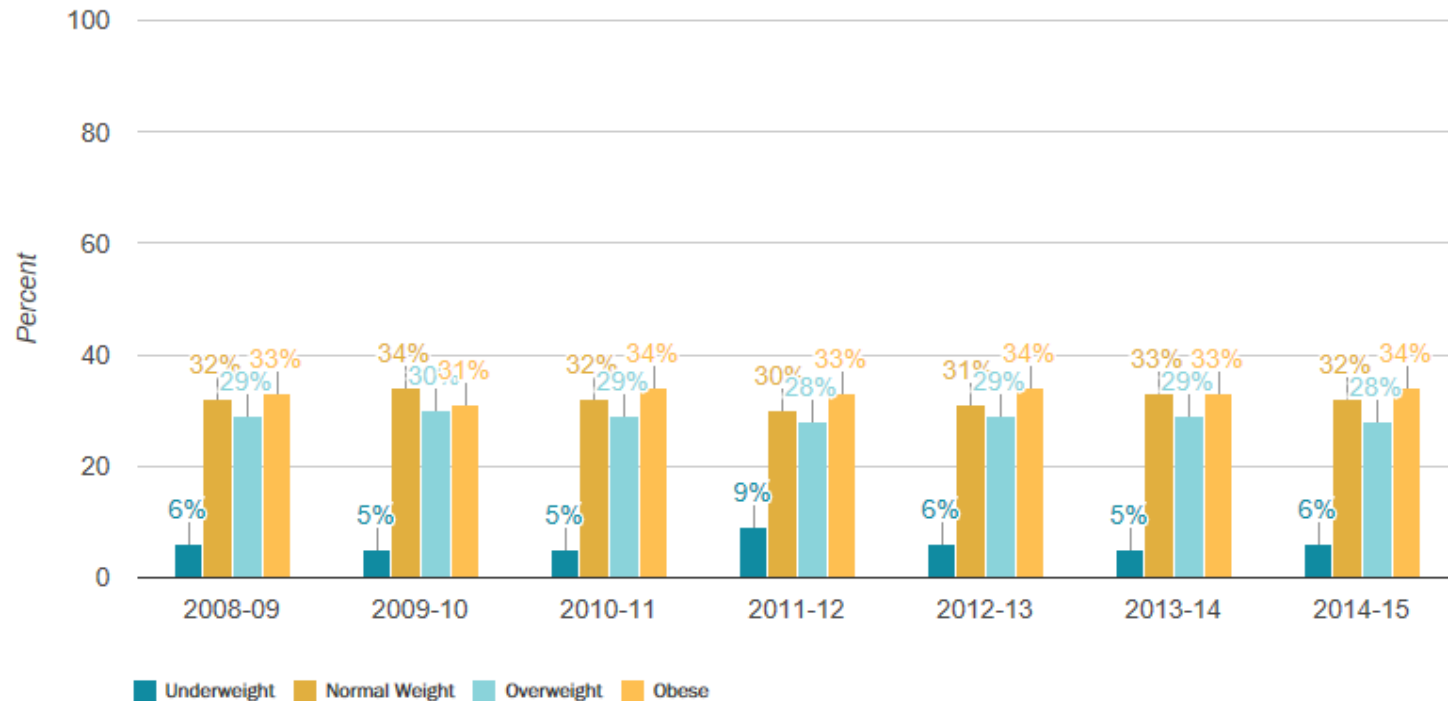


Obesity



BMI- Body Mass Index

The proportion of people who maintain healthy habits in such areas as smoking, weight, and exercise.



Hitting Close to Home...



- Obesity → Costs
 - heart disease, hypertension, diabetes, hyperlipidemia

Model-adjusted median and mean health care expenditures by BMI status.

	Neither Overweight nor Obese (BMI < 25)		Overweight		Obese	
	Median	Mean	Median	Mean	Median	Mean
Non-IDD Overall	\$3108	\$3920	\$3684	\$4086	\$4578	\$5134
Non-IDD Per user	\$3431	\$4256	\$3978	\$4464	\$4789	\$5524
IDD Overall	\$4485	\$4997	\$4037	\$7076	\$5421	\$7462
IDD Per user	\$4780	\$5393	\$4300	\$7439	\$5980	\$7909

Note: "Overall" includes expenditures that are zero, whereas "per user" only includes non-zero expenditures.

67-73% higher!

43-45% ↑

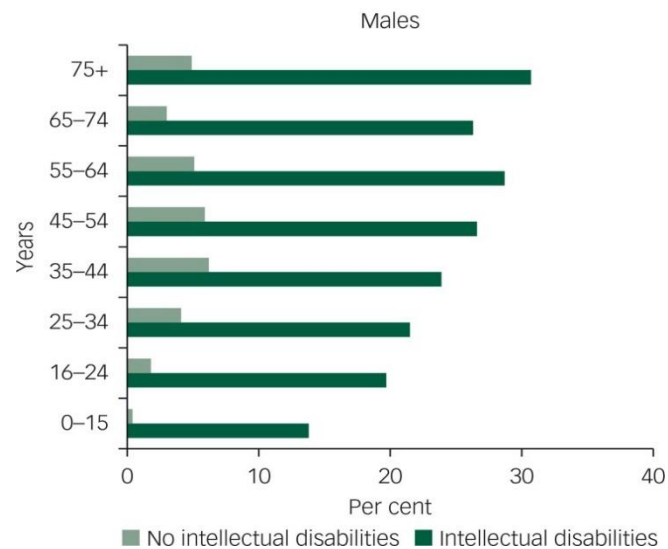
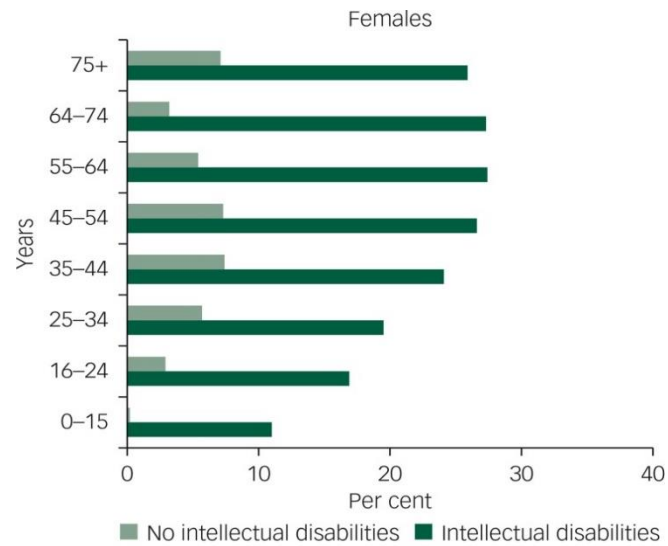
Mental Health



Prevalence of mental ill health in the populations with and without intellectual disabilities

Age group	Intellectual disabilities, n/N (%)			Other people, n/N (%)		
	Male N=15 149	Female N=11 200	All N=26 349	Male N=2 552 295	Female N=2 716 759	All N=5 269 054
0–15	450/3253 (13.8)	218/1981 (11.0)	668/5234 (12.8)	1739/465 853 (0.4)	914/445 244 (0.2)	2653/911 097 (0.3)
16–24	492/2501 (19.7)	281/1661 (16.9)	773/4162 (18.6)	5664/314 382 (1.8)	9113/313 944 (2.9)	14 777/628 326 (2.4)
25–34	436/2025 (21.5)	286/1450 (19.7)	722/3475 (20.8)	13 552/326 582 (4.1)	19 330/337 270 (5.7)	32 882/663 852 (4.9)
35–44	529/2209 (23.9)	398/1650 (24.1)	927/3859 (24.0)	22 004/355 461 (6.2)	27 633/375 434 (7.4)	49 637/730 895 (6.8)
45–54	653/2456 (26.6)	490/1845 (26.6)	1143/4301 (26.6)	22 723/382 061 (5.9)	29 384/400 394 (7.3)	52 107/782 455 (6.7)
55–64	442/1539 (28.7)	363/1324 (27.4)	805/2863 (28.1)	16 581/325 383 (5.1)	18 207/339 167 (5.4)	34 788/66 4550 (5.2)
65–74	212/805 (26.3)	208/762 (27.3)	420/1567 (26.8)	6776/224 557 (3.0)	8106/255 668 (3.2)	14 882/48 0225 (3.1)
75+	111/361 (30.7)	137/527 (25.9)	248/888 (27.9)	7741/158 016 (4.9)	17 770/249 683 (7.1)	25 511/407 654 (6.3)
All ages	3325/15 149 (21.9)	2381/11 200 (21.3)	5706/26 349 (21.7)	96 780/2 552 295 (3.8)	130 457/2 716 759 (4.8)	227 237/5 269 054 (4.3)

Mental Health



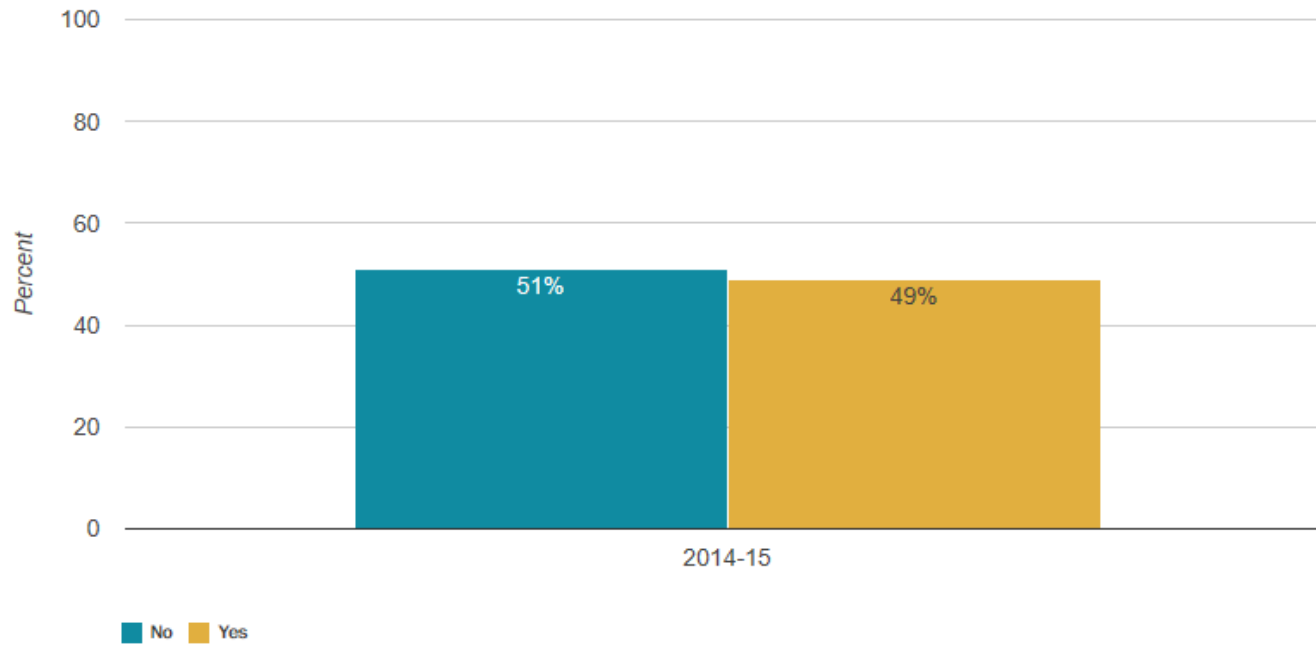
Mental Health



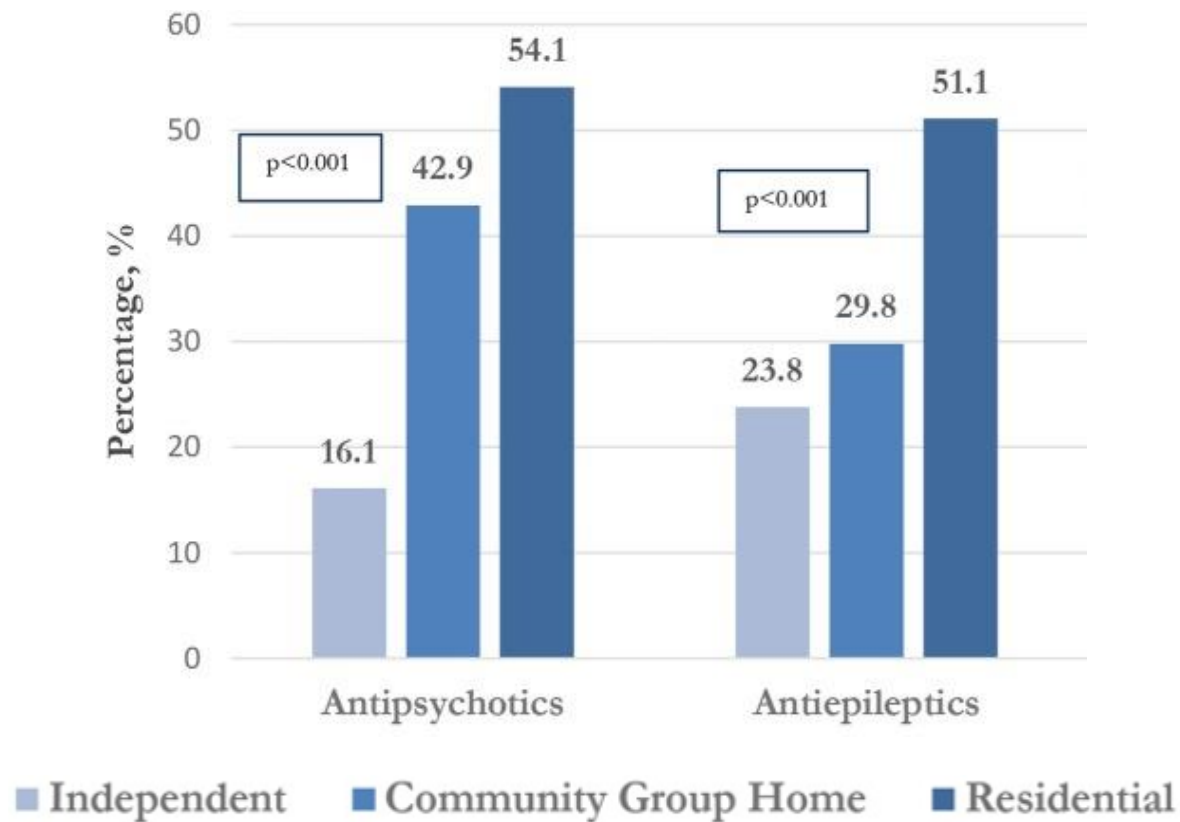
Takes medications to treat mood disorders anxiety and/or psychotic disorders 2014-15



The proportion of people who currently take medications to treat mood disorders, anxiety and/or psychotic disorders



Polypharmacy



People with polypharmacy are more likely to die than people without.



Culturally competent health home for people with IDD.

			
FQHC	Mental Health Center	RCCO/ACC	IDD Provider
Medical	Mental health/Psych	Care Coordination	Care Int., Behavioral
Cost-based <u>reimb.</u>	Medicaid state plan	Medicaid pm/pm	GF, FFS, Med Waiver



DDHC Patients

Sample = 576

- 66.3% high or very high risk
- 0.64 ED visits
- \$42,188 tot. Medicaid
– Polypharm (data as of 2/28/2017)

Non-DDHC

Sample = 1077

- 34.1% high or very high risk
- 0.30 ED visits
- \$54,065 tot. Medicaid
(+28%)

	2015	2016	2017
DDHC	\$2114	\$2448	\$2418
Non-DDHC	\$2675	\$3019	\$3222
<i>dif</i>	<21.0%>	<18.9%>	<25.0%>

Data are as of 12/31/2017 unless noted.



Weight Loss

POWERSforID¹

- Avg. weight loss = 5.6
(control = +2.2)

HRQoL

MFP Q: “Are you happy with the way you live your life?”

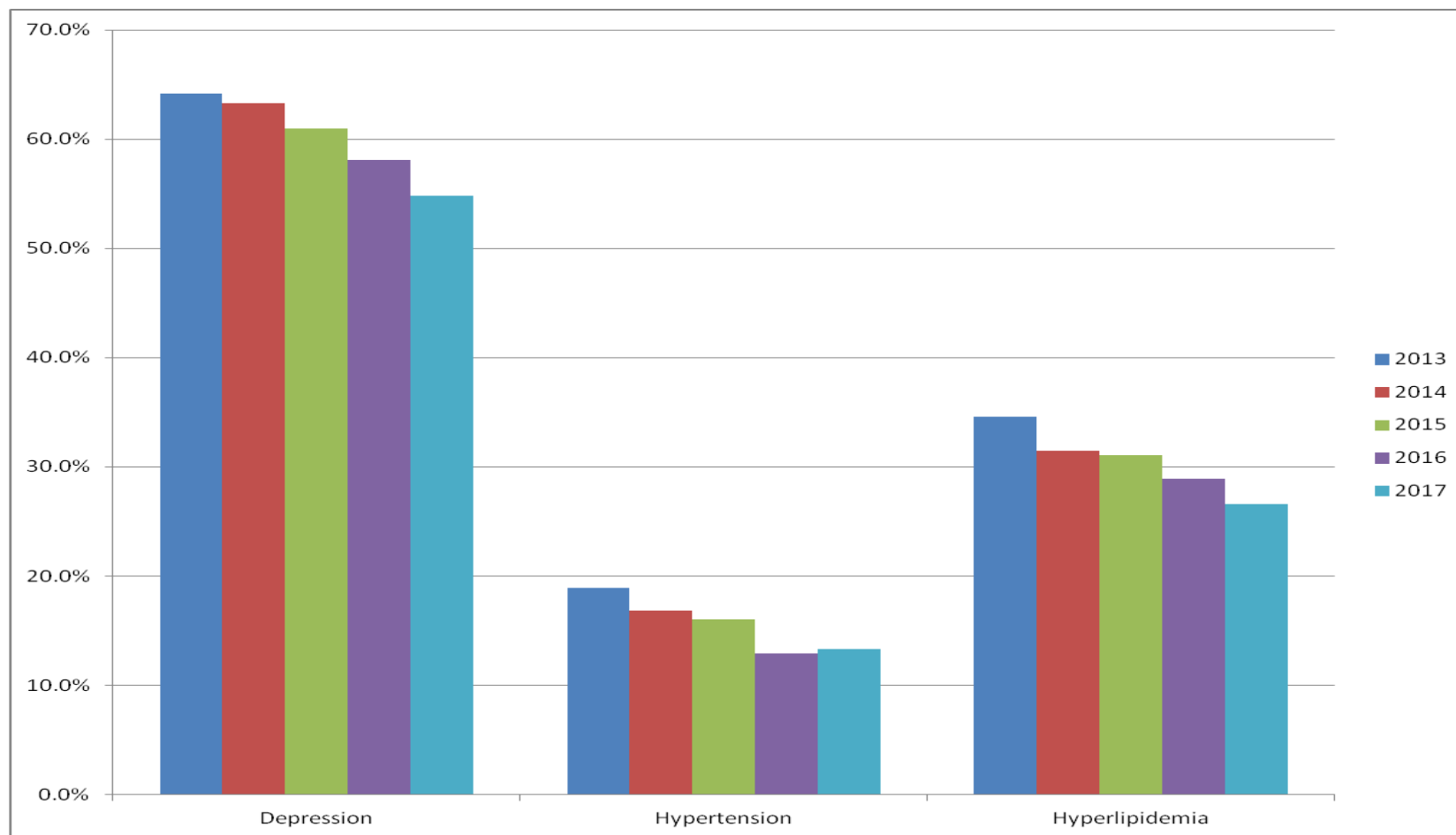
DDHC ≥ 6 mos.	DDHC 0-6 mos.
76.4%	59.2%

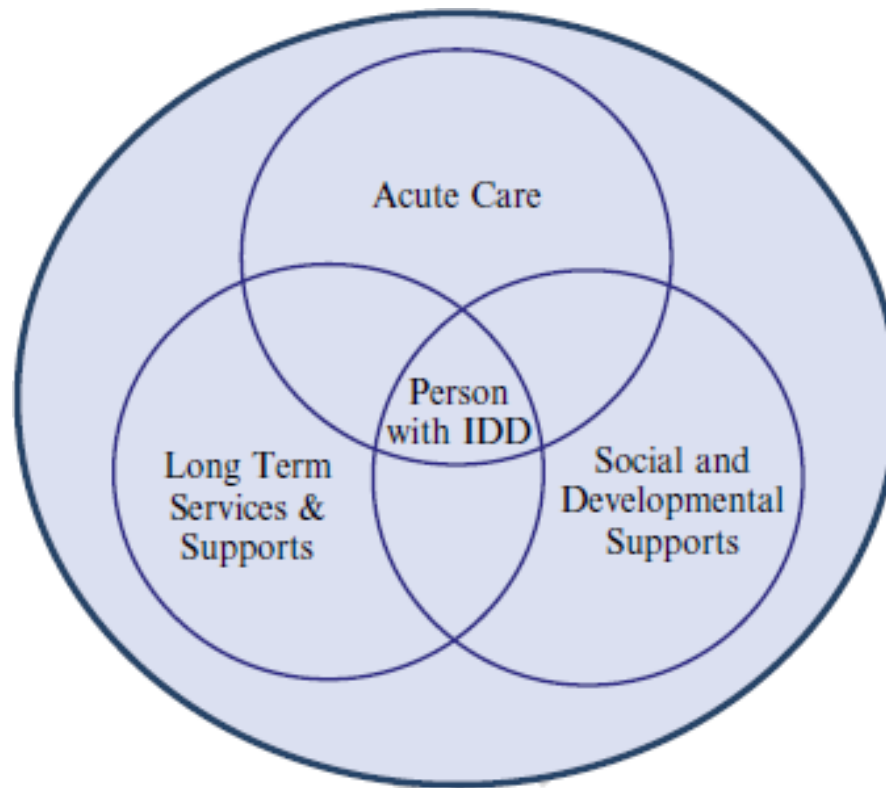
p=0.088

¹ Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD), funded by the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant # 90RT5020-03

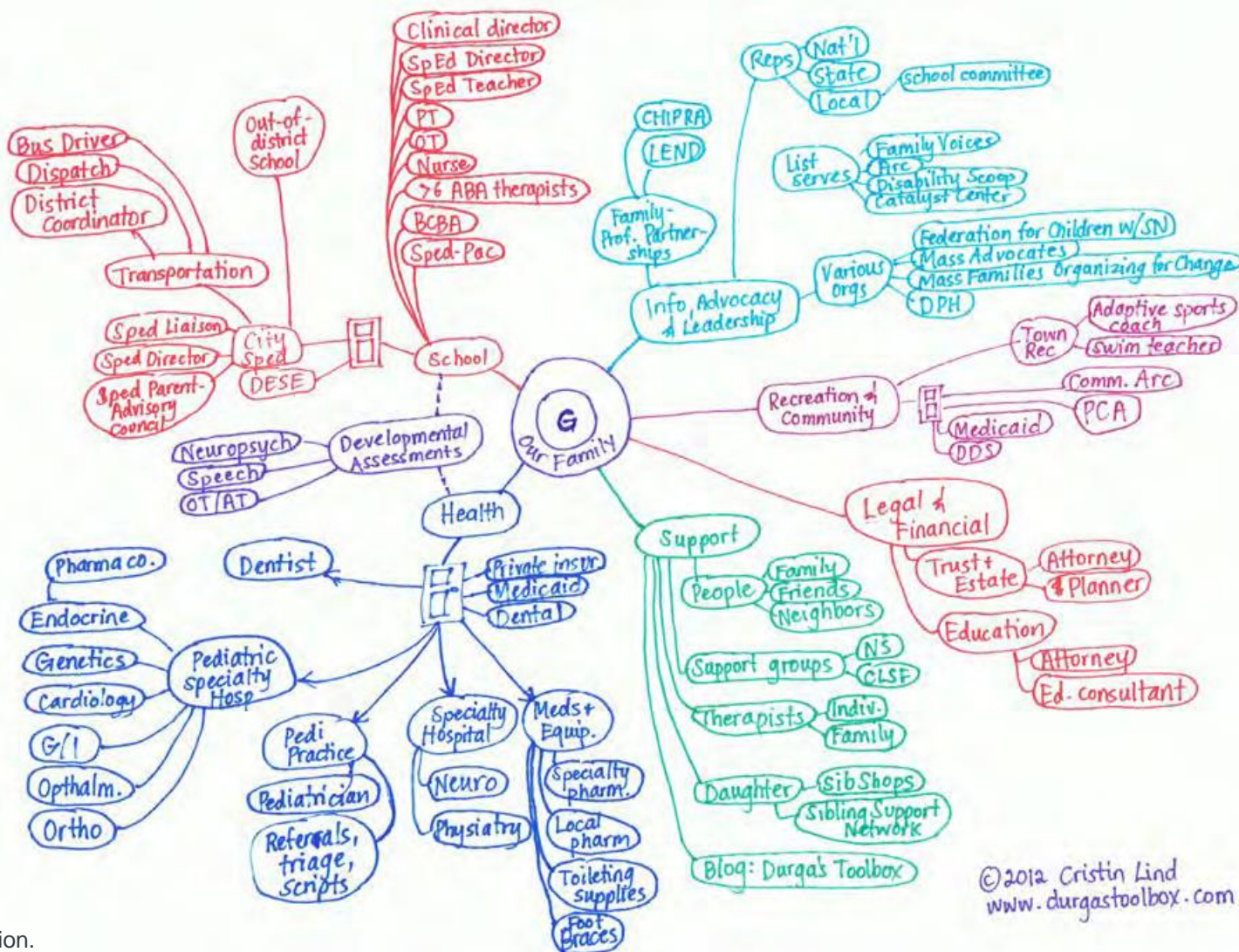


Cross sectional view of the DDHC Population 2013-2017 (Jan 1 thru Dec 31)





Oh. My. Gawd.



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www.durgastoolbox.com



- It's as bad as we have always known!
- Culturally competent care more likely to deliver better health outcomes
 - Different, less expensive healthcare utilization
 - Improved clinical/bio-markers
 - Health related quality of life
- Interdisciplinary, integrated health neighborhoods





WHAT DO WE WANT?



HEALTH EQUITY



WHEN DO WE WANT IT?



imgflip.com

NOW!



Barriers



- Financing Systems
 - High costs (disproportionality)
 - Conveyor Belt medicine
 - Disincentives to integration
 - Bi- and Tri-furcated systems of care
- System Capacity
 - Physicians, dentists and other health science practitioners not trained in Developmental Medicine
 - Transitions to adult med a big deal!

Barriers



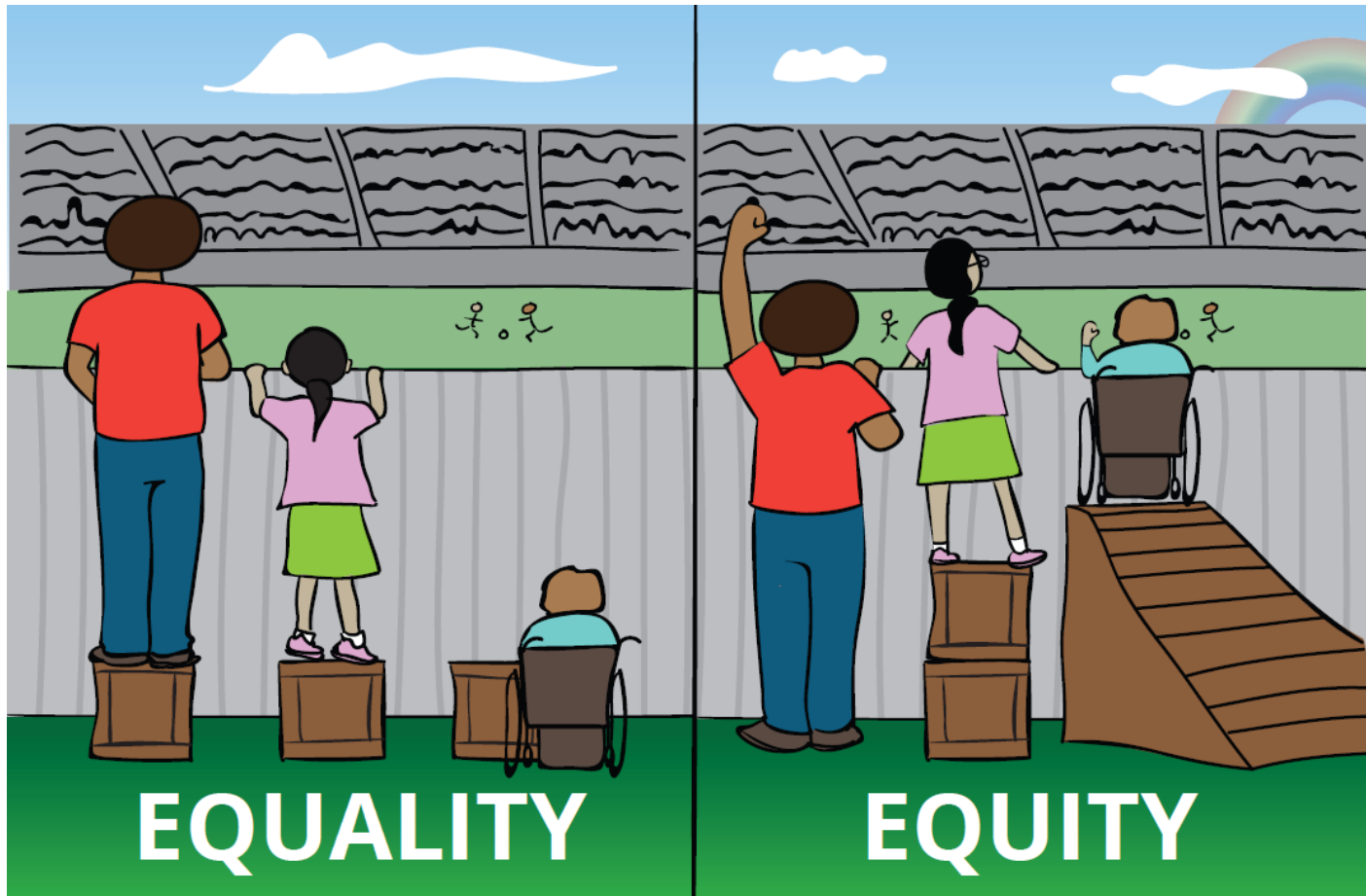
- Policy Threats
 - Healthcare Reform
 - Block-granting Medicaid
 - Pre-existing conditions
 - Medicaid Managed Care
 - Why is MUP so hard?
 - LTSS Reform
 - Work requirements
 - Block-granting Medicaid
- Attitudinal Barriers
 - “Oh, that’s just the Autism actin’ up!”

Barriers



- Others?

Health Advocacy



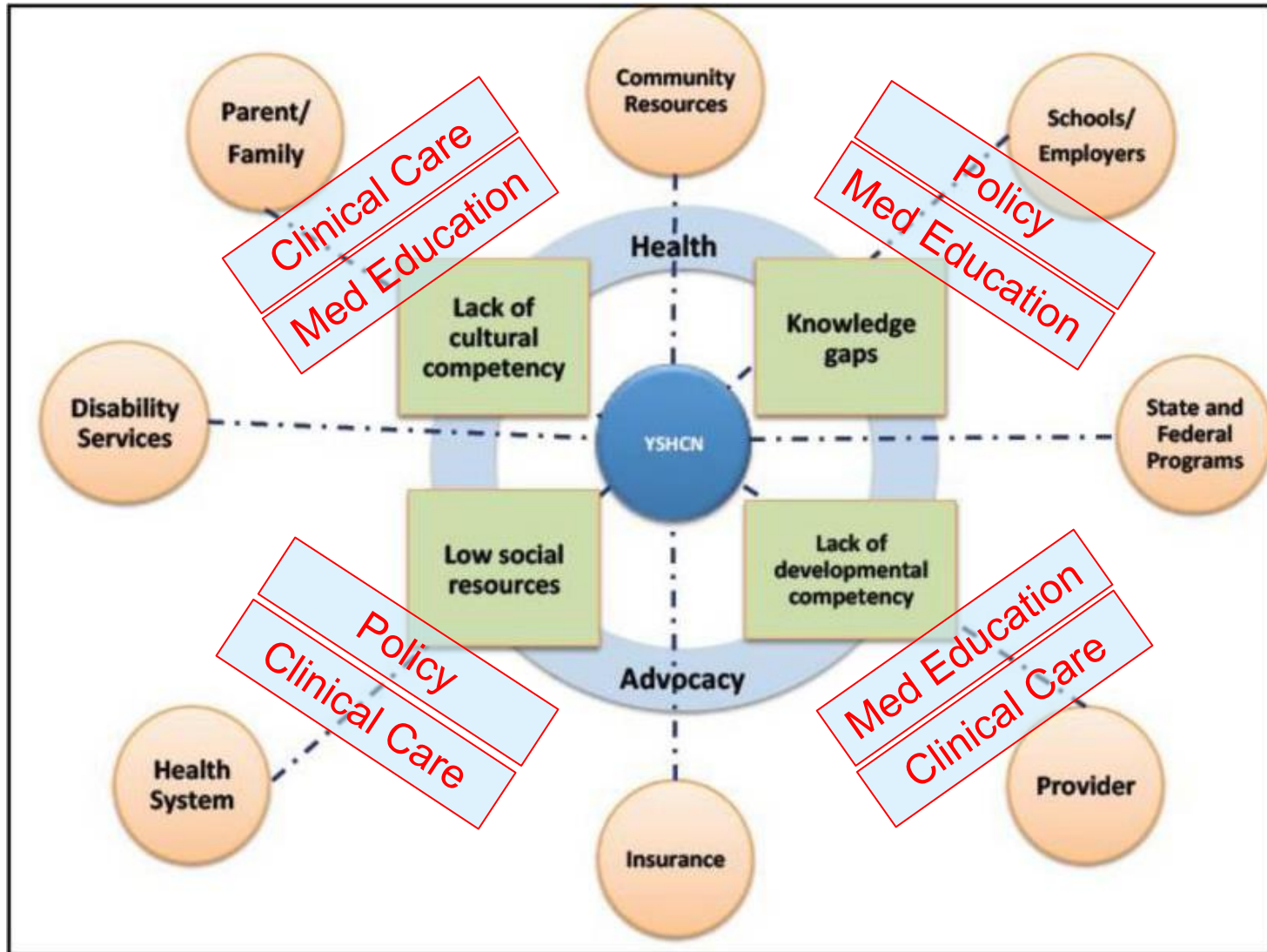
Health Advocacy



A deliberate attempt to influence decision makers and other stakeholders to support or implement policies that contribute to improving health equity using evidence.

Individual, community and systems

Health Advocacy



Health Advocacy



- Policy
- Clinical Care
- Health/Medical Education
- And, don't forget the evidence?
 - What are your data?
 - What data are you collecting
 - To what purpose?

A rectangular metal mailbox, likely made of galvanized steel, is mounted on a light-colored, textured wall. The mailbox features a central horizontal slot with a brass-colored finish. Inside this slot, the word "LETTRES" is embossed in a serif font. The mailbox is secured to the wall by four screws, one in each corner. The overall appearance is that of a classic, functional outdoor mail delivery point.

-

policy

Clinical Care



- Attitudinal Barriers
 - “Oh, that’s just the Autism actin’ up!”
 - Pediatricians and 53 year-olds
 - Absence of options (Medicaid panels ‘closed’)
- Healthcare Reform
 - Pre-existing conditions
 - Medicaid Managed Care
 - Why is MUP so hard?



Education



- Developmental Med curriculum
 - Boards—specialty or subspecialty
 - Practical training opportunities

“Because of limited formal training in medical school and residency, few physicians have the clinical competence and comfort level required to treat people with disabilities. A survey commissioned by Special Olympics found that only 25% of medical schools include content regarding people with intellectual/developmental disabilities in their curricula.”

(Woodard, Haverkamp, Zwygart & Perkins, 2012)

What Else?



Action Plan



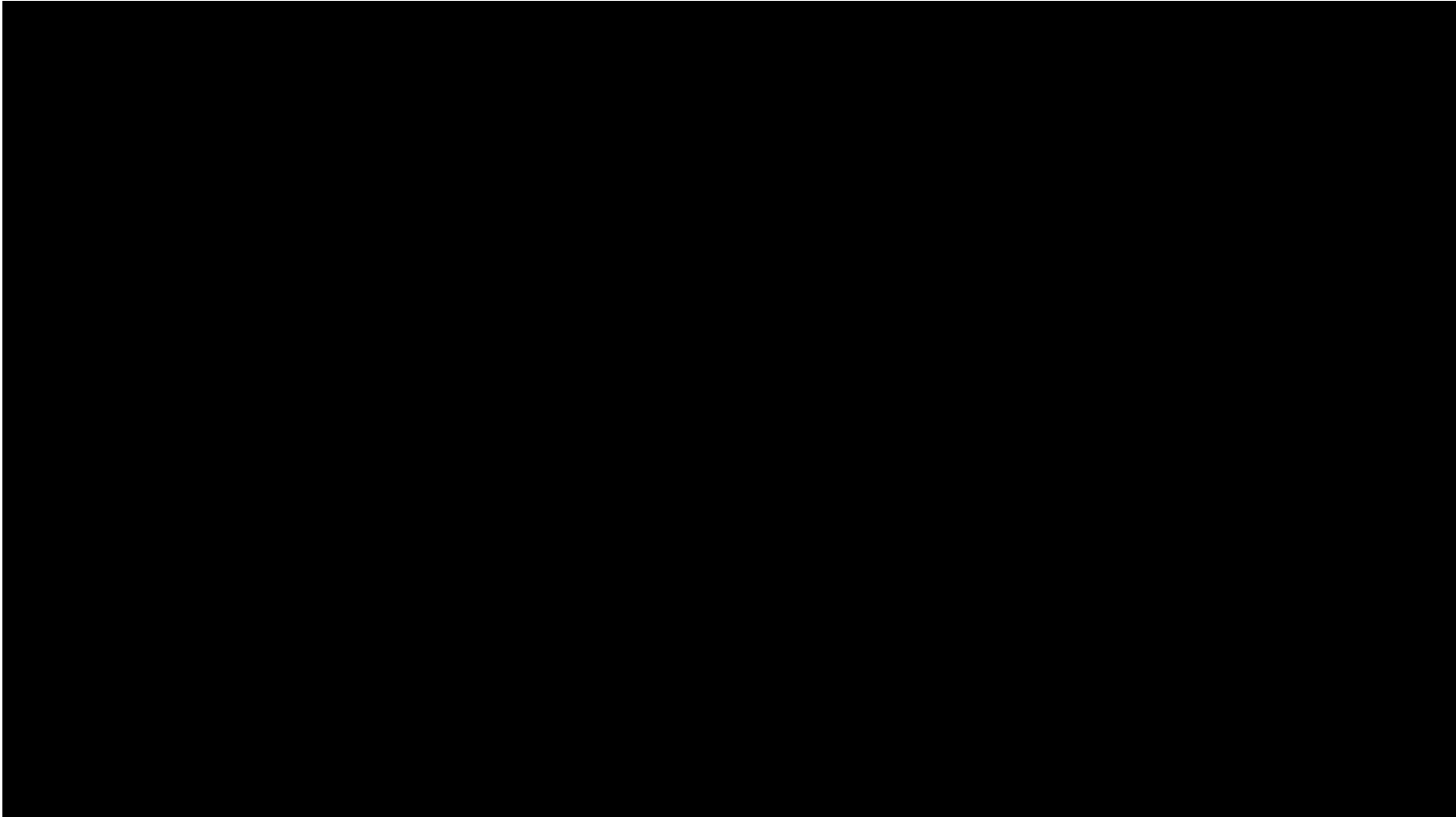
- What are our priorities?
 - Top three
- Who or what can help us?
 - DDNA? AADMD? AAIDD?
 - Your organization?
- Self-Advocates, families & professionals
- What do we need to do?
- By when-ish should these things be done?
- How will we know if we are successful?
- How do we stay connected and engaged?

Action Plan

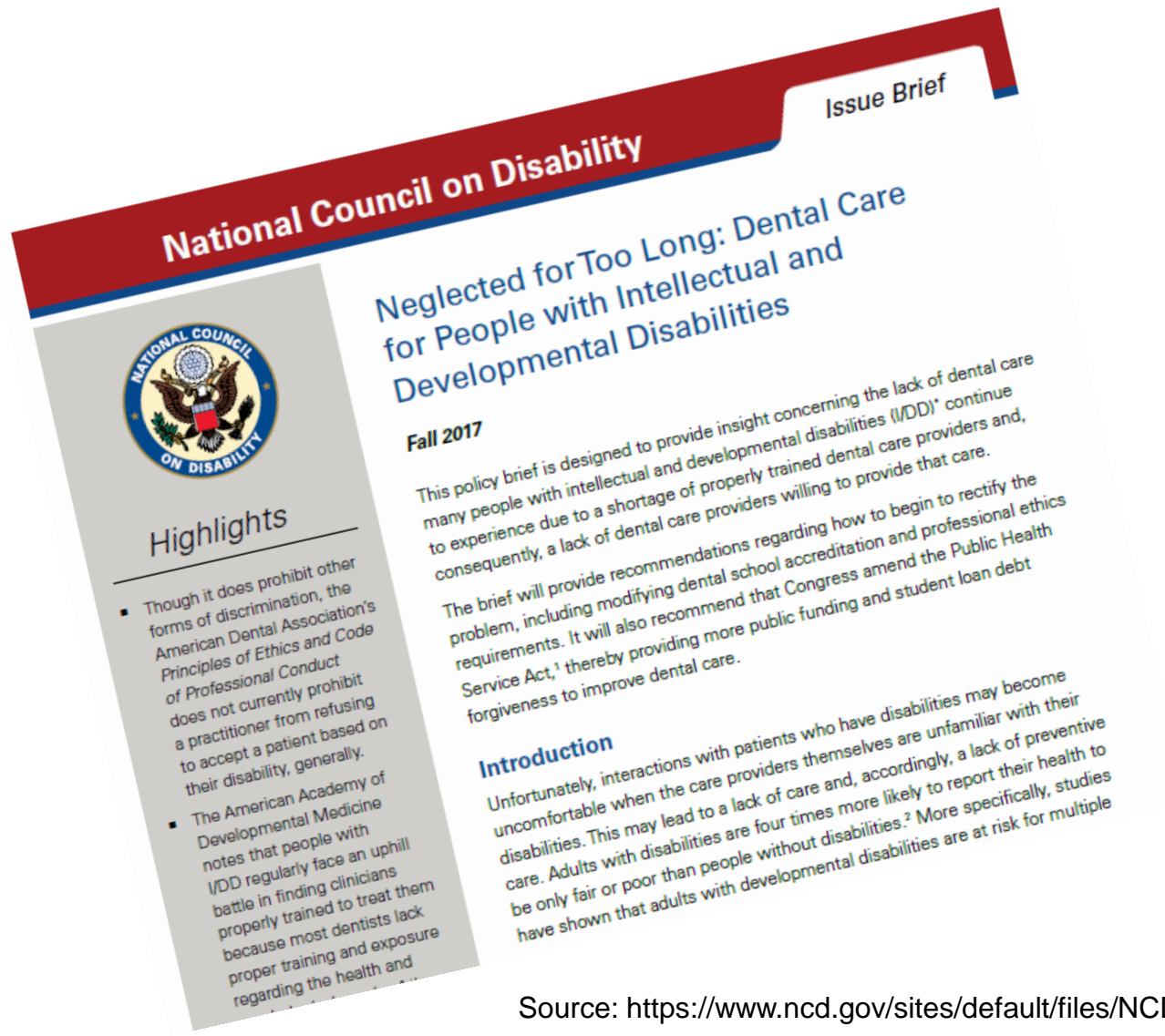


<div> <div> <div>Search...</div> <div>Upgrade</div> <div>29 Days Left</div> </div> </div>									
<div> <div>Home</div> <div>Action Plan</div> <div>Create New</div> </div>									
<div> <div>No Filter</div> </div>									
				Goal / Action Steps	Description / Desired Outcome	Party/Department Responsible	Date to Begin	Date Due	% Complete
1				Goal 1	Policy: Change financing	The Resource Exchan	04/02/18	06/30/19	0%
2				Analyze DDHC data on health outcomes	Lower high-cost utilization	TRE Research Center	02/25/18	03/25/18	100%
3				Analyze DDHC data on health outcomes	Lower bio-maker: Cholesterol	DDHC	02/25/18	03/25/18	100%
4				Analyze DDHC data on health outcomes	Improve HRQoL	DDHC/TRE Research (02/25/18	03/25/18	100%
5				Present outcomes data to Health Care Po	Funding innovation pilot	David	07/02/18	09/01/18	25%
6				Goal 2	Write your goal 2 statement here	Department 2	01/02/17	03/31/17	44%
7				Action step 1	Desired outcome	Employee 5	01/02/17	03/31/17	25%
8				Action step 2	Desired outcome	Employee 6	01/02/17	03/31/17	25%
9				Action step 3	Desired outcome	Employee 7	01/02/17	03/31/17	75%
10				Action step 4	Desired outcome	Employee 8	01/02/17	03/31/17	50%

Outcome



Outcome



Source: https://www.ncd.gov/sites/default/files/NCD_Dental%20Brief%202017_508.pdf

Resources



www.aadmd.org/policy-statements



<http://aaid.org/news-policy/policy#.WpMnlkxFyUk>



<https://www.thearc.org/what-we-do/public-policy>



<https://www.specialolympics.org/health.aspx?src=navwhat>



<https://ctb.ku.edu/en/table-of-contents-community-assessment/choosing-strategies-to-promote-community-health-and-development>



Resources



<http://www.stateofthestates.org/>



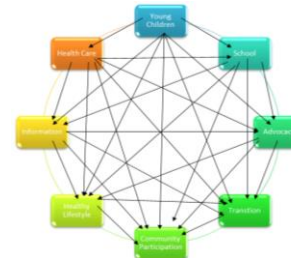
<https://www.kff.org/>



<https://ddna.org/forums/>



<http://www.eparent.com/education/a-gps-for-families-of-people-with-special-needs/>



<https://withfoundation.org/blog/>



Resources



<https://www.nationalcoreindicators.org/>



<https://www.ncd.gov/policy/health-care>



<https://www.aahd.us/>



<http://www.ncsl.org/research/health.aspx>



NATIONAL CONFERENCE of STATE LEGISLATURES

<http://www.adhce.org/>



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The task is not yours to complete, but neither are you free to desist from it.

Pirke Avot 2:21

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